Huntington's Disease Association

Magazine

Summer 2019

Is that wedding bells I hear?

Huntington's disease is hard to swallow but can we change that?

Fundraising volunteers reach for the stars

An interview about Huntington's disease genetic testing

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In this edition

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For advice or support from one of our Specialist Huntington's Disease Advisers visit:
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Welcome

We are pleased to share the latest edition of our magazine with you.

It's been a busy few months. Our event calendar began with our young adult events - the Inbetweeners' day and Decisions, dilemmas and discussions helping to support those aged between 18 and 45 affected by Huntington's. (Page 26) Understanding Huntington's disease - our flagship training event, designed to increase knowledge and understanding for health and social care professionals, was held in May. We were pleased to hold our annual Juvenile Huntington's disease weekend again – a weekend of zip wires, canoeing, horse riding and a Disney themed party! (Page 27)

We were thrilled to hold our fourth annual volunteer fundraising awards to celebrate and thank our volunteer fundraisers for raising awareness and funds for us. Huge congratulations to all award winners and nominees and thank you to everyone who has taken the time to support us during the year. We continue to be amazed by your achievements and generosity. (Page 4)

Huntington's disease awareness month saw many of you shine a light on Huntington's disease via your social media, holding local events, asking local buildings to light up, contacting media and even lighting up your own homes – raising awareness and capturing the attention of thousands of people who knew little or nothing at all about the disease before. What an amazing achievement. (Page 22)

We continue on our journey to increase understanding of Huntington's disease and improve quality care and support and we watch with hope as Huntington's research progresses. (Page 10)

We look forward to seeing many of you at the family weekend in October!

Thank you

Cath Stanley
Chief Executive

Andrew Bickerdike
Chair of Trustees

Volunteer fundraising awards 2019 winners!

YOUNG VOLUNTEER OF THE YEAR AWARD WENT TO...

ELI AND ISAAC GREER

"We played piano and sang as part of the Tickle the Ivories event over three slots at Liverpool ONE in August and managed to raise a fabulous sum for the Huntington's Disease Association. We are hoping to raise even more in 2019!"

Our fourth volunteer fundraising awards ceremony was one of the best yet! Nominees came from all over the country to join us on the 1 June at the Birmingham Park Regis hotel for a meal and ceremony. This year, we had two categories from which winners were chosen. Our adult's category, Most Inspiring Volunteer, gave the chance to vote for two inspirational volunteers. Whereas our children's award, Young Volunteer of The Year, allowed for one vote. Our finalists included some incredible and inspirational Huntington's Disease Association volunteer fundraisers, but there could only be three winners!

We are so proud of all our volunteers and want to thank everyone for their attendance. Congratulations to not only our winners but to everyone who dedicates their time to fundraising and raising awareness of Huntington's disease.

AWARD FOR MOST INSPIRING VOLUNTEER WENT TO...

ROSIE ALLEN

"I ran the London Marathon to help aid the fundraising efforts we do every year as a family for the Huntington's Disease Association. I also organised a charity ball for the March before the marathon to support my fundraising, this was such an amazing night that everyone enjoyed and we had so many amazing prizes."

JO HAGUE

"Last year was a big year for us as a family, particularly for my older sister Clare. She decided to be tested for Huntington's disease. So, I decided to apply to for a Golden Ticket to run the London Marathon. Supporters also turned up to a quiz night and a fashion show that I organised, my uncle Ian hosted a special art exhibition of his own artwork and my school even chose the association for a charity dress down day."

Exemplar Health Care

PJ Care specialised neurological care

National Association of Funeral Directors raise vital funds

We were delighted to attend the recent Annual Ball of the National Association of Funeral Directors at the Mandolay Hotel in Guildford where a fantastic £1,600 was raised towards our work. NAFD President Abi Pattenden had kindly nominated the Huntington's Disease Association to be her chosen charity during her Presidency. Thank you to everyone who attended and gave so generously.

National Association of Funeral Directors

Park Regis Hotel Birmingham pull out all the stops

Our partnership with Park Regis Hotel in Birmingham goes from strength to strength with the hotel providing us with rooms for meetings and events – all of which help us to direct our income towards our services. We still have another full year to work with Park Regis Birmingham and we look forward to hearing all about their staff fundraising over the coming months.

PARK REGIS
BIRMINGHAM · UK

Marathon joy

This year has proven to be a huge year for marathons. Our brilliant fundraisers have taken the challenge to a new level by taking part in the London Marathon, Manchester 10K, Liverpool Rock 'N' Roll Marathon and more! At the London Marathon, we had 27 brave runners taking on 26.2 miles who raised £49,450.65 for us! Emma Fletcher, one of our dedicated supporters and Girls Football Development Manager for Manchester United Foundation, and her team took on the Manchester 10K raising £5,655.91. In total, our Manchester 10K runners raised a whopping £14,634.34!

Paperchase take the lead for Huntington's

We are thrilled to have been chosen as one of the charities to have a charity Christmas card designed by Paperchase. The cards will be available to purchase in Paperchase stores nationwide from September onwards. The Huntington's Disease Association will also have a presence on their website under the charity card section. This will help to bring Huntington's disease and the work we carry out to a larger audience.

FMP Global

FMP Global ride to victory

We are well into our partnership with FMP Global as their Charity of the Year with staff taking part in sweepstakes and office fundraising. They have a big event planned in July 2019 – the Paris to Chichester cycle ride! Good luck to everyone taking part!

Coral James shed a light on Huntington's

East Midlands Estate Agents, Coral James have named the Huntington's Disease Association as their Charity of the Year for 2019 – 2020. They have already got their support off to a fantastic start by taking part in Huntington's Disease Awareness Month lighting up lots of their properties in the local towns and villages where they operate. We look forward to working with Coral James over the coming year.

Marks and Spencer, Liverpool charity of the year success

Marks and Spencer on Edge Lane, Liverpool have announced the Huntington's Disease Association as their Charity of the Year for the forthcoming year. They are doing lots of fundraising in-store as well as having an information display about Huntington's disease and the work we do.

Get involved

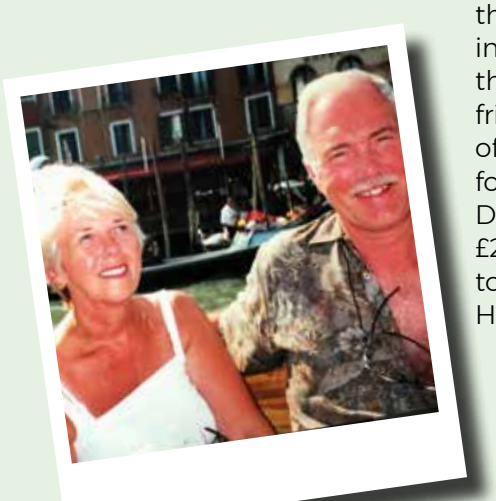
Does your place of work run its own Charity of the Year scheme or fundraising days? They may even offer matched-funding or payroll giving. If they do, please consider nominating the Huntington's Disease Association to help raise more funds to support more people affected by Huntington's disease.

If you have any questions about workplace fundraising or matched giving, contact the fundraising team for more information at fundraising@hda.org.uk

Is that wedding bells I hear?

Roger England and Anne Potter from Old Edlington, Doncaster have been together for 22 years. During this time they have travelled the world together on various holidays. More recently these trips have been cruises both near and far, with their favourite destination being the Caribbean. Closer to home they have been keen walkers with regular trips into the nearby Peak District as well as more occasional trips to the Lake District and Dunure in Scotland.

Roger received a formal diagnosis of Huntington's disease in 2010 which came as a surprise because it was the first diagnosis in the family. Despite this devastating blow, Roger and Anne remained keen to continue enjoying their life to the full.



Until a couple of years ago, Roger played lead guitar in a band formed with four neighbours who practised in the keyboard players converted dove house. Their gigs were kept very exclusive but did become a regular part of the Old Edlington village New Year's Eve celebrations. In 2010, after his diagnosis, Roger and Anne hosted a garden party at their home and as part of this Roger and the other members of 'Four Play' entertained a small gathering of friends and family. During this event, Anne and Roger raised £1000 for the Huntington's Disease Association.

Roger and Anne were married at their home on 23 February 2019. Also taking part in the morning ceremony were many family members and some close friends. The celebrations continued through the afternoon and into the evening during which they were joined by many more friends and neighbours. Instead of wedding presents, they asked for donations for the Huntington's Disease Association and received £200 which they donated towards supporting Juvenile Huntington's disease.

"In a time when it is too easy to be negative towards the NHS and associated health care professionals, Roger, Anne and their families would like to give special thanks to all medical professionals who have done an amazing job supporting Roger after his condition progressed towards the end of 2018. Without their support and flexibility, the wedding might not have been feasible."

James England, son of Roger

A huge congratulations to the lovely couple and a massive thank you for all they have done for the Huntington's Disease Association.

Branch and support group review update

In 2018, the Huntington's Disease Association contacted all Branches and Support groups to offer a series of consultation opportunities about the role of the groups. We were delighted with the response and a Branch and Support Group Steering Committee was set up to look at the issues raised.

The Steering Committee now have a number of pieces of work in progress, all of which came out of the 2018 consultation, these include:

Branch and Support Group structure
We are working on clearer definitions and supporting documentation

Update of the Branch Declaration and Support Group agreement
We are working to make these clear, consistent and concise

Finances
Changes have been made and communicated to the groups

Webpages
We are working with our web designers to establish what the branch pages on the Huntington's Disease Association's website will look like. There will be a space for each group to give information about their group and who to contact

There for each other.

Branches and support groups

If you are interested in getting involved with a local group or finding out more about what's happening in your area visit www.hda.org.uk/branches

What's happening in the world of research?

Currently, there is a lot happening in the field of Huntington's research, from drug trials to social studies, researchers are donning their lab coats and getting to work. If you or your family are affected by Huntington's disease the pace of progress may feel slow but, in fact, things are moving quickly in research terms. Here, you can see some of the research that is happening at the moment.

Genentech

Genentech is a member of the Roche group and they are running a phase three trial with a drug called RG6042 (formally known as IONIS-HTTRx). RG6042 is an antisense oligonucleotide (ASO), these are a short string of DNA-like molecules that can stick to Huntingtin RNA and stop the Huntingtin protein from being produced. RNA is a message molecule, based on DNA, used by cells as the final set of instructions for making a protein.

The aim of this trial is to show whether this drug can slow down the progression of Huntington's or improve symptoms for people with the disease. They will be recruiting people who have early symptoms. The sites in the UK for this next stage of the trial have just been announced but recruitment hasn't begun yet.

Uniqure

Uniqure is looking into a prospective Huntingtin lowering therapy. They are using a small harmless virus which carries instructions to a specific gene in the body that helps cells lower Huntingtin levels. Viruses can't access the brain themselves so are injected using a very fine needle. The advantage of viral therapies is that the effects can last longer. Uniqure plan to start a trial with patients with early symptoms of Huntington's in the future.

Precision-HD

Precision-HD is a trial being run by Wave Life Sciences. They are testing Huntingtin lowering therapies in two trials – precision HD 1 and 2. The trial involves delivering antisense oligonucleotides (ASOs), into the brains of people affected by Huntington's. The ASOs act by binding to the mutant Huntingtin protein, mRNA, therefore preventing the formation of the toxic mutant Huntingtin protein. The drug specifically attacks mutant Huntingtin RNA and leaves the healthy form of the protein mostly intact.

Voyager Therapeutics

Voyager Therapeutics is also developing a Huntingtin lowering therapy based on a viral delivery, a tool used to deliver genetic material into cells, with the aim of reducing Huntingtin in targeted cells. They aim to inject the drug into the thalamus. The thalamus is a part of the brain with several important functions such as relaying sensory signals and regulating of consciousness, sleep and alertness.

PTC Therapeutics

PTC Therapeutics is looking at a different approach to Huntingtin lowering. They are using small molecule drugs that can be taken as a tablet that will specifically target genes. The idea is that PTC will selectively flag the Huntingtin messenger to be degraded. They hope to begin human trials in 2020.

Huntington's disease is hard to swallow – but can we change that?

"Our research is the only clinical trial in the world investigating swallowing in people affected by Huntington's disease"

Swallowing problems are common in Huntington's disease. People with Huntington's often notice problems chewing, controlling food in their mouth and coughing or choking during mealtimes. There are also associated problems with weight loss, malnutrition and food or drink going down the 'wrong way' which can cause chest infections or pneumonia.

If you, or someone you care about, experiences these difficulties, you should seek a Speech and Language Therapy referral for assessment and personalised advice. Your GP or local Huntington's disease adviser will be able to help you arrange this. You may be advised to alter your diet to help adapt to swallowing difficulty. However, there are currently no therapies to improve or slow the decline of swallowing problems in people with Huntington's disease.

Recognising the importance of helping those with difficulty swallowing, we are part-funding Emma Burnip's PhD research into swallowing therapy for people with Huntington's located in New Zealand.

The therapy Emma Works on currently consists of two weeks of training using a type of computer game for your swallowing. They use the most up to date technology to measure many different elements of swallowing in people with Huntington's. The first part of their research has been presented at the World Swallowing Congress in Barcelona and the European Huntington's Disease Network conference in Vienna.

"I worked as a Speech Therapist in the UK and I was frustrated that I couldn't offer my patients with Huntington's disease any proactive exercises to keep their swallowing safer for longer. So, with the support of the Huntington's Disease Association, I gave up my job in the NHS and moved to Christchurch in New Zealand where there is a world-renowned swallowing research centre. I am now more than halfway through my PhD research. Our research is the only clinical trial in the world investigating a new swallowing therapy for people with Huntington's disease.

We are very excited that over the next few months we will have lots of information to present and share with the Huntington's disease community, Speech and Language Therapists and Swallowing researchers around the world." – Emma Burnip

Enroll-HD
Enroll-HD is a worldwide observational study for Huntington's disease families. It monitors how the disease appears and changes over time in different people and is open to people who either have Huntington's or are at-risk. It is managed by the CHDI foundation whose aim is to better understand Huntington's disease, to give insights into developing new drugs and rapidly develop therapies that slow the progression of Huntington's. They are actively trying to increase the numbers of people who have predictive tests but are not yet showing symptoms. This helps to develop a better understanding of Huntington's in these people but also creates a group of potential patients who are available to participate in any up and coming clinical trials.

To learn more about the research that we support, follow www.hda.org.uk/research

Your genetic testing questions answered

In this article, Dr Alan Fryer answers some commonly asked questions about genetic testing.

What is the initial process for someone who is considering genetic testing?

There are two types of genetic test:

Diagnostic testing

This is used when a person has symptoms of Huntington's disease. It is undertaken by doctors who think their patient may have Huntington's disease with the appropriate consent of the patient and family.

Predictive testing

This is used when a person has no symptoms but has a close relative who has been diagnosed with Huntington's disease or carries the gene. Predictive testing is undertaken in the UK by departments of Clinical Genetics after genetic counselling has taken place and a period of reflection.

Genetics services are based in most major cities in the UK either at a Genetic centre or a clinic held at a local hospital.

What are the genetics of Huntington's?

Huntington's disease is caused by a faulty gene that can be passed on by a parent who has the disease. People with a parent affected by the disease have a 50% chance of inheriting it themselves. A gene is a piece of biological information inherited from your parents, it is present in every cell of the body and tells cells what to do. It is usually attached to a chromosome - a strand of DNA containing many different genes. Each cell in the human body contains around 25000 genes and most have 23 pairs of chromosomes. DNA is made up of four chemicals – A (Adenine), T (Thymine), C (Cystosine) and G (Guanine). One section near the start of the Huntington's gene (chromosome pair four) contains three of these chemicals C, A and G which are repeated over and over again (i.e. CAG,CAG,CAG,CAG etc.) causing an expansion. It is this increased level of repeats that makes the gene larger than normal and causes the disease to develop. Up to 27 CAG repeats is considered normal and the person won't develop Huntington's disease. Most people with the disease have one copy of the gene with more than 40 repeats.

How is the genetic test taken?

The genetic test itself measures the number of repeats in two copies of the Huntington's disease gene. This is done via a blood sample.

Before the process can begin for someone undergoing predictive testing, a person must have genetic counselling to make sure they want to take the test and are prepared for the potential result. Usually they need to be over the age of 18.

What do the results of the genetic test tell the patient and medical professionals?

If the test reveals two normal copies of the Huntington's disease gene (i.e. within the normal range of repeats), the person will not develop Huntington's disease, nor will their children or future family generations. If however one copy of the gene contains 40 or more repeats, the person will develop Huntington's disease at some stage in the future and each of their children face a 50% risk of also developing the disease.

Very occasionally a result can be obtained that can result in some uncertainty. If one copy of the gene contains between 27 and 39 repeats, there is a chance that there could still be a risk to future generations as the gene can expand further as it's passed on. If the number of repeats in

one copy of the gene is between 36 and 39, there is a small chance the person could develop Huntington's still (though the majority of people do not).

In what way can genetic testing affect the person after receiving the results?

The genetic test result, regardless of the outcome, can affect people differently. Some people find relief in knowing that they will go on to develop the disease rather than continuing at 50% risk, allowing them to plan ahead. Many people who test positive, use the result as their motivation to live their life to the full before Huntington's symptoms take hold and spend time raising awareness of the disease.

Other people who have lived at risk and have mentally prepared themselves for a possible life with Huntington's can find it difficult to adapt to the news that they won't go on to develop it. They may also experience feelings of guilt that they have escaped the disease when a loved close relative is affected.

Do you have any advice for people considering genetic testing?

Everyone's situation is different. Deciding whether or not and when to have a predictive test is a major decision and only you can make it. My advice is to seek a referral to your local Clinical Genetic Service where you will see genetic counsellors and doctors with a lot of experience who can provide information to help you make an informed voluntary decision about taking a test. It is important to know that you can withdraw from the process at any time – going through the process does not mean you are obliged to take the test.

How can people who are confused about whether to test or not come to a final decision?

Deciding whether or not to have a predictive test and when to have it is a major decision. Only the person can decide whether they want to be tested or not. Usually, they need to be over the age of 18 and the test should not be undertaken without genetic counselling and a period of reflection.

What does the genetic testing process involve?

The typical process involves an initial session where:

- The person provides details of their family history to the doctor or genetic counsellor at the session who then attempts to confirm the diagnosis history by checking the results of prior family tests.
- The doctor or genetic counsellor provides information about Huntington's disease and the genetic test process and possible results.
- The person will discuss with the genetic counsellor their reasons for requesting a test at this stage in their life and their approach to the possible outcomes. There will also be a chance to discuss, if wanted, the reproductive options available if the person wants to avoid the possibility of passing the disease on to the next generation.
- The person will be given the chance to identify someone who will support them through the process.
- The person will be encouraged to think about and discuss the impact any result will have on their family or friends. This can be particularly important in relation to other family members who may not wish to be tested themselves but where the test could also reveal their status.
- The person will be encouraged to consider financial implications and other issues such as life insurance and employment.

This initial session is followed by a summary letter and then a period of reflection. If the person wants to continue with the process, a second session is then arranged during which:

- A review of the information discussed at the first session is undertaken.
- The doctor / genetic counsellor, in accordance with genetic testing guidelines, may consider a neurological examination and a psychological appraisal to better evaluate the person. This, however, is not a requirement for participation in predictive testing.
- The person and genetic counsellor will discuss preparing for the results.
- Dates are arranged for a blood sample to be taken and a follow up appointment (usually a month after) to discuss test results face to face. Relevant follow up sessions are arranged as required after results are given.

Positivity is key

An interview about Huntington's disease genetic testing

If one of your parents is affected by Huntington's disease there may be many questions circulating in your mind. One of the most pressing being, 'do I want to be tested for the Huntington's gene?' This is an extremely hard question to answer and one that should not be made lightly. In the UK, you must be 18 years or older to begin the testing process and this begins with several months of counselling to prepare you for your result. In this interview, we hear from Josh as he talks us through how his life is affected by Huntington's and what it was like to go through Huntington's disease genetic testing.

Who is Josh?

My name is Josh, I am from Bridlington, East Yorkshire and have always lived there. I am 21 years old and have four brothers and two sisters, I am the youngest.

What's your connection to Huntington's disease?

In my family, my mother's side is where the Huntington's disease originates, her father had Huntington's and passed it down. My mother passed away in her 40s from Huntington's and for most of my childhood, I only remember her being quite symptomatic with Huntington's. I was ten years old when she passed away. It was difficult because as a child I was never really fully aware of why my mother wasn't very well, as Huntington's is a big thing for children to comprehend. I think it was after my mum actually passed, it was then that I began to fully comprehend Huntington's and what it was. I always felt as though I couldn't speak about what I was feeling after my mum passed away because I didn't want to bring up an emotional subject with family members and because I didn't know of anyone else with Huntington's, I didn't think my friends would understand. As I got older, it became easier and I had great support from my siblings and close friends.

Why did you decide to get tested?

I decided to get tested after both my brother and sister got positive tests back for Huntington's. It was always something that would play on my mind, the not knowing was dreadful. As soon as I turned 18 I went and spoke to my GP and he referred me to a genetic counsellor to get tested for Huntington's.

What was the testing process like for you?

The process was long, about six months from start to finish, it felt a lot longer. The counsellors were lovely and very helpful at

Castle Hill Hospital and I had the amazing support from my boyfriend (now my fiancé). The support helped massively with my down days, I think if I didn't have this, I could've quite easily got very depressed and other problems could've occurred from this.

"...whatever the test result, take it as either a blessing and make the most of your life, or take it as an excuse to make the most of your life..." Josh

How did you feel after getting your result?

The day I actually went to pick up my results was awful. I was waiting around for three hours in the Hospital. I was initially upset at this but I was told there had been lots of bad results to give out to people that day and the aftercare had resulted in being very behind schedule. I remember as soon I walked into the room my counsellor just told me to take my time. At that point, I knew deep down it wasn't good news. I could tell by the small talk and lead up to the result. "I'm really sorry Josh, but it's not good news". I felt strange and it's hard to explain, I just felt numb. I think I was expected to break down into tears but I didn't. I thought I was lacking in emotion but really I was just bottling everything up and later on that day when I got loads of text messages and phone calls off of friends and family asking if I was ok, it then started to sink in. Especially when I spoke to my auntie over the phone and I could hear a disguised cry in her voice.

How did you come to terms with your result?

I came to terms with my result over the coming months as I decided I wasn't going to mope around and dwell on what is to come. I knew that would never be the case as I am a positive person. I decided that I would make the most of the rest of my life and had a totally fresh perspective on life, I was going to live life to the fullest. I was and still am at my fittest and am at a prime age for making memories. I also decided I would make a pact to do my bit to raise money and awareness for the Huntington's Disease Association as the support they give is amazing. In 2016, I took part in a three-day trek of the Swiss Alps, covering Switzerland, France and Italy across 40 miles of trekking. It was an incredible and life-changing experience. I made lifelong friends who regularly make the effort to meet up with me even though they live a six-hour journey away in London. I raised over £3000 for this challenge. I have taken part in other charity challenges and I am currently raising money for a trek of the Grand Canyon that me and my fiancé are taking part in this September.

Do you have any advice for people considering genetic testing?

The only advice I could give to people is to turn a negative situation into a positive one. Either way, whatever the test result, take it as either a blessing and make the most of your life, or take it as an excuse to make the most of your life as you don't know when the Huntington's will kick in."

We hope that Josh's inspirational and honest story has given an insight into the testing process. But remember, testing is not right for everyone and every person is different. In the end, you are the one who must make the decision to be tested.

If you are affected by Huntington's disease and would like advice on genetic testing please get in touch with us on info@hda.org.uk or call 0151 331 5444

ADVICE

Understanding medication for Huntington's disease

Deciding on medications for someone affected by Huntington's disease can be very difficult due to the fact that you don't directly treat the disease, you treat its symptoms. This can mean that a huge array of medications are available for the person affected, therefore fathoming their symptoms and the right medication to suit them can be confusing. In this article, Professor Hugh Rickards at the University of Birmingham discusses medications for a range of Huntington's disease symptoms.

What types of medication are out there?

There are a number of medications out there that can help to manage the problems that Huntington's disease causes for people and their families. At the moment, there are no medications in existence that can stop or reverse the underlying problem. Those sorts of treatments are being researched currently but they can't be routinely given in the clinic.

What kind of symptoms can be treated?

The sorts of problems that can be helped with medications are as follows; low mood (depression), anxiety, irritability (short temper) and jerky movements. Most of those problems will have other treatments too that should be considered alongside, or instead of, the medications. This might include changes in the environment and in the way other people interact with the person who has Huntington's disease, physical exercise and adaptations.

Some Huntington's disease-related problems can't usually be treated with medication. These include apathy, memory difficulties, planning problems, problems with social understanding and balance. In these situations, there are often non-medication treatments and strategies that can be used.

Where to find medications

Firstly, you need to work out what the problem is before deciding if medication is the answer. For this, you need to see a doctor. This is usually the GP at first but then they may need to ask for help from the specialist if you have one. All of the medications above can be prescribed by a GP and collected from a pharmacy.

Some specialist treatments have to be prescribed by the specialist. Some medicines aren't available at some pharmacies, but they will always try and get hold of the medicine as long as it is available in your country.

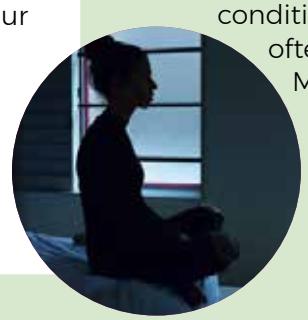
Most symptoms should be managed with a combination of approaches with medication as one part of a bigger plan.

Symptoms and accompanying medications

Depression and anxiety

These are common conditions in Huntington's disease patients but also in those who are caring for people with Huntington's disease. They often occur together. The main symptom of depression is an issue with enjoying everyday experiences such as drinking a good cup of tea, enjoying a programme on the TV or radio or seeing family. When this problem extends to all situations, all of the time, it's often time to think about medication.

Anxiety comprises of excessive worry and often includes physical symptoms like a feeling of a lump in the chest, fast heart beating, sweating and wanting to run away. There are many medication treatments for these conditions and they can often be effective. Mild side effects are common but often wear off over time.



The common treatments are in a group called SSRIS, which boost a chemical called serotonin in the brain. When taking these treatments, people can often feel more agitated for the first few days but this almost always wears off. Other common side effects are feeling a bit nauseous, changes in sleep pattern and in sexual function (often harder to reach orgasm). Most of these problems wear off with time or with a slightly lower dose, so it's important that more than one person is aware that the medication is being consumed. Of course, there are lots of other things that can be done as part of the treatment of depression and anxiety, including exercise, good diet, regular routine, meditation and being with friends. Some types of counselling can also be helpful.

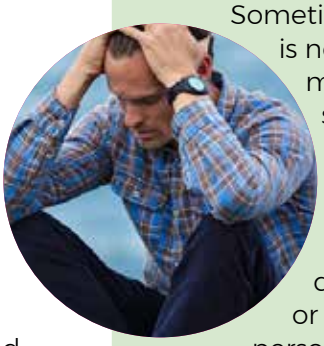
Irritability

Irritability is really common in people affected by Huntington's disease. In fact, most people with Huntington's have periods of becoming short-tempered. This is usually because they find it difficult to understand some social situations or they become overloaded with things to think about. In people who have more advanced Huntington's disease, irritability may happen because of another physical problem that the person is not able to communicate such as pain, constipation or infection, so it's important to try and rule that out. Before going for the medication option, it's usually best to really look closely at the types of situations where a person with Huntington's disease might become irritable. There's usually a pattern if you look hard enough. This means that other people might be able to change their approach to prevent temper outbursts, rather than using medications.

There are very many different types of medication used for irritability. There are no high-quality studies in this area so treatments are usually based on experts talking to each other and comparing treatments. Usually, irritability is treatable with a combination of medication and changes in the environment including changing the way other people relate to the person with Huntington's disease.

Excessive movement

Huntington's disease was often thought of as solely a movement disorder. This is why it used to be called Huntington's chorea, as chorea meant 'dancing movement'. This was probably because it was the most obviously 'different' thing about a person with Huntington's disease. However, this is not a very useful way to look at it because jerky movement is not something that usually bothers people with Huntington's disease and, in most cases, it's not what stops them doing the things that they want to do. As well as this, medications for excessive movements can often make people feel low in mood and make it harder for them to think clearly.



Sometimes, medication is needed to reduce movements. The sorts of situations where this can be useful are when jerky movements are disturbing sleep, or throwing a person off balance, or leading to injury. In those situations, people use a variety of medications that block the effect of a brain chemical called dopamine. Examples of these medications include risperidone, olanzapine, tetrabenazine, sulpiride and haloperidol. These sorts of medications quite often will reduce jerkiness but can often lead to more sleepiness and stiffness. Weight gain is a common effect of these drugs (especially olanzapine) but sometimes this is a good thing for Huntington's disease as part of a strategy for keeping weight up. This group of medications can sometimes make people feel down in their spirits and they find it difficult to motivate or develop stiffness in the limbs or body.

Sometimes people with Huntington's disease or their relatives want to treat the jerky movements to prevent the relatives from feeling embarrassed or judged by other people. This is not usually a good reason to give medications which can have negative effects.

Top tips on oral health

The teeth of someone with Huntington's disease are no different from those of someone without the disease, but people with Huntington's do present clinically with more dental problems. This is primarily due to difficulty in cleaning the teeth properly and clearing the mouth of food after eating.

Diet
Almost all foods contain enough sugar to cause decay, but some foods such as milk, contain protective factors.

Mouth care
The correct and regular use of dental floss and an electric toothbrush help prevent tooth decay. Toothpaste that contains fluoride can also help. Specialist equipment is available and community dentists may be able to make a home visit.

Before bed
As saliva flow is much less during sleep, food clearance is slowed. It is therefore advised not to eat within half an hour of going to bed.

Fluoride treatment
Toothpastes and mouthwashes with more than the normal concentration of fluoride can help in fighting tooth decay. It is also advisable to have a dentist apply fluoride to the teeth in a stronger solution, or as a slowly dissolving varnish, during regular check-ups.

Care by dentist
A dentist can de-scale the teeth to prevent gum disease, apply fluoride to improve the resistance of the teeth (raising the frequency of intake threshold) and detect early cavities. If they know that a patient is at risk of Huntington's disease, they can choose specific filling materials (such as glass ionomers) that, although being a little more brittle than silver amalgam, do tend to increase resistance to decay. Normal cavity design can sometimes be modified with a view to preventing decay. Design of partial dentures should take Huntington's into account and should therefore have extra retention to counteract excessive dislocating forces.

Legacies

Leaving a gift in your Will for the Huntington's Disease Association

Over the past few years, gifts from the Wills of our supporters have become an incredibly important part of our income at the Huntington's Disease Association.

Making a Will

The importance of making a Will cannot be underestimated. A Will makes it much easier for your family or friends to sort everything out when you die – without a Will, the process can be more time consuming and stressful for your loved ones.

The latest research from www.unbiased.co.uk from 2018 shows that almost 60% of us in the UK have not made a Will. If you don't write a Will, everything you own will be shared out in a standard way defined by the law – which isn't always the way you might want.

Writing a Will is especially important if you have children or other family who depend on you financially, or if you want to leave something to people outside your immediate family or your favourite charity, such as the Huntington's Disease Association.

Gifts in Wills and the Huntington's Disease Association

We are incredibly grateful for every gift, large or small we receive at the Huntington's Disease Association. Our work supporting people, families and carers affected by Huntington's disease simply could not happen without the generosity of our supporters.

The income we receive from gifts in Wills allows us to make plans for the future, to ensure that we'll be there for people affected by Huntington's disease for years to come. In the past year, we have supported thousands of people affected by Huntington's disease – from one to one support through our Specialist Huntington's Advisory Service to our specialised weekend events such as the Family Weekend and JHD Weekend; our booklets and guides are available for health and social care professionals as well as individuals seeking more information on the many different aspects of Huntington's disease. Our Welfare Grants scheme provides direct financial support to those who desperately need it. The demand for our services grows each year.

Leaving a gift in your Will to the Huntington's Disease Association is easy to do. You will need to speak to a Solicitor to ensure your Will is drawn up correctly. Once you have taken care of your family and friends, should you choose to, you can add in a gift towards our work. You will need the following details to ensure your gift reaches us:

Huntington's Disease Association, Liverpool Science Park IC1, 131 Mount Pleasant, Liverpool, L3 5TF
Registered charity number 296453 (England and Wales)

Your Solicitor will be able to recommend the wording you can use.

Help finding a Solicitor

The Law Society can help you find a solicitor in your area. For more information, call 020 7242 1222 or you can visit their website www.lawsociety.org.uk and use the Find A Solicitor function.

Keeping us informed

We'd love to hear from you if you have already left a gift in your Will for the Huntington's Disease Association or if you are planning to leave a gift for us. Letting us know your plans means we can thank you properly and helps us to make plans for the future. What you choose to tell us is not legally binding and it will be treated with the utmost respect and confidentiality.

You can contact us at fundraising@hda.org.uk

We collaborated with award winning social documentary photographer Stephen King to create an impactful awareness exhibition, giving our contributors a chance to tell their story and curate their own portrait.

Inherent: a Huntington's disease story

Margaret's story

"I first came into contact with Huntington's when I married my second husband Arthur. He was tested two years after we were married and he tested positive. He did tell me that it was in the family. But he wasn't aware of it affecting himself because he was an older man, he was sixty-nine when I first met him.

It was only the last couple of years of his life he went really downhill. We were in an apartment then and we didn't want him to be a prisoner so we put our name down for a bungalow with the council and never looked back. He really had the best life since we came here. He loved it. He went to all the activities. It gave him the life that he wouldn't have had. "We're living each day as if it was our last", that's what Arthur said to me when he was diagnosed. He used to go to the bar and talk to everybody.

I've done line dancing for years, he used to come to the club with me. When we have the line dancing Huntington's charity events, the girls put his picture on the stage. Now it's not the same if his picture's not there, so we make sure every time we have one of the events for the picture to go on the stage. He's with us all the time. Even though he was ill, he lived his life and everybody you speak to...all would say what a lovely lovely man he was. He was such a gentleman.

I've got more involved with the charity side of things with the Huntington's Disease Association since he's died; the thing is, it keeps me going. It's not well known and I like to make people more aware of what it is."

"We were in an apartment then and we didn't want him to be a prisoner so we put our name down for a bungalow with the council and never looked back. He really had the best life since we came here. He loved it. He went to all the activities. It gave him the life that he wouldn't have had." – Margaret

Awareness month extravaganza

This year we extended our awareness week to a full month! This gave us a real opportunity to try to raise the profile of Huntington's with the help of our wonderful supporters. Buildings and houses lit up across the world as part of the international #LightItUp4HD campaign which also drummed up some local press interest. There were multiple carer events run by our Specialist Huntington's disease Advisers, our Carer's guide was launched and our in-depth Understanding Huntington's disease course for professionals took place. There were also lots of stories and perspectives shared on our social media channels and website.

Awareness events

Supporters across the country held their own Huntington's disease awareness month events to help bring Huntington's disease out of the shadows. All around the UK, people were invited to tea parties, bake sales, information events and raffles in both support of our work and to bring knowledge of Huntington's to those that may never have heard of it before.

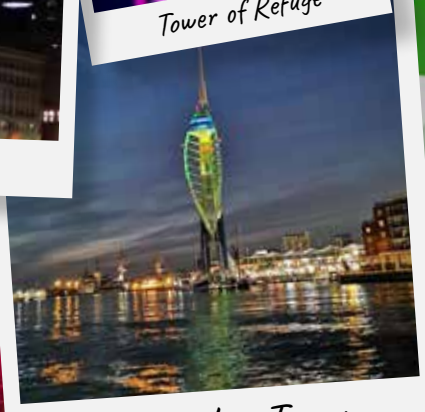
Spotlight on carers

Our specialist advisers spent time throughout the month delivering training to care professionals. They organised peer support events for family carers and handed out our brand new Carer's guide.

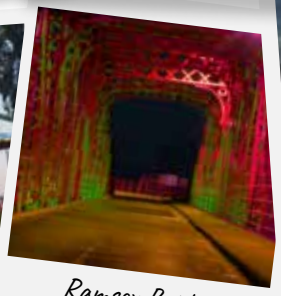

Althorp Estate


George's Dock


Tower of Refuge


Spinnaker Tower


Steve Prescott Bridge


Ramsey Bridge

#LightItUp4HD

Huntington's disease charities and organisations across the UK and the rest of the world joined forces throughout May to light up buildings and landmarks to raise awareness of Huntington's disease. People even lit up their own homes with the help of our #LightItUp4HD packs!


Blackpool Tower


Weymouth Pavilion


Fullwell Mill


Havenmere care home


Seaburn Lighthouse


Wyvern Theatre

During May we used our social media channels to share stories of those affected by Huntington's and posted infographics to help people learn more about the disease. Our supporters added Twibbon frames (digital frames that have the Huntington's Disease Association's logo and Awareness Month written on them) to their social media profile pictures and lit up digital stars in the sky to remember their loved ones via VisuFund. We succeeded in getting several online news articles published relating to the #LightItUp4HD campaign while writing blog articles on our website that helped raise awareness of Huntington's.

Join us for our Family Weekend

"Feeling normal with people who are experiencing many of the issues we face was invaluable. It was great to hear expert advice and information."

18 - 20 October 2019 Radisson Blu Hotel, East Midlands Airport

Learn more about Huntington's, meet others living with the disease and find out what's new in Huntington's care, research and management.

Find out more and book your place

Book online at www.hda.org.uk/get-involved/events or complete and return the enclosed booking form. If you have any questions contact us on 0151 331 5444 or info@hda.org.uk.

* Formal notice of the AGM can be found on our website
Speakers and workshop topics may be subject to change.

Talks

- Dr Ed Wild from University College London on Huntington's research progress and current trials
- Josh Beasley on his Huntington's disease testing journey
- Cath Stanley, Chief Executive of the Huntington's Disease Association, on the work of the charity

Workshops

- Genetic testing for Huntington's
- Managing mental health and related behaviour changes
- Practical tips on diet and nutrition
- Planning for end of life
- The importance of physical activity and physical therapy
- Relaxation techniques

What else is happening?

- Saturday evening is a formal dinner with a Disney theme disco
- An offsite trip and activities will be available for children and young people
- There will be opportunity on Sunday for any branch and support group members in attendance to discuss the progress of the current branch and support group model review and put forward their ideas and suggestions
- This weekend incorporates our AGM and the chance for questions to be put to our Board of Trustees*

BUPA funding success – online support for carers aged 65+

We are delighted to announce that the Bupa UK Foundation has awarded us funding for a year-long project to look at online support for people aged 65 and over caring for people with Huntington's disease.

We know how much digital technology has progressed over the last few years and whilst these advancements make information more accessible to some, for others, particularly the older generation, it can be a real challenge. Many people in the 65+ age group may not have used computers as much throughout their lives as the younger generations and so navigating the web may not be second nature as it is to some. We recognise that online information is the way forward and thanks to BUPA we have the opportunity to make online information more accessible for carers aged 65 and over – one of the key groups our charity engages with.

We plan to create online resources designed specifically with, and for, this user group. The resources will provide user-friendly access to practical advice, peer support opportunities and health and wellbeing tools.

But for us to do this, we need your help! If you are aged 65 or over and care for someone with Huntington's, would you be willing to help us with this project? If so, contact Ruth Abuzaid, Head of Service Development at the Huntington's Disease Association, for more information at ruth.abuzaid@hda.org.uk

Carer's guide – new edition available now

Do you care for someone affected by Huntington's disease? If so, take a look at our Carer's Guide, created specifically with carers in mind. This comprehensive guide covers everything from information on organisations that offer support, to advice on emotional wellbeing. You can download the PDF guide from our website and refer to it when needed or we can provide hard copies on request.

www.hda.org.uk/getting-help/if-youre-a-carer

Huntington's Disease Association
Quality Assured

Quality Assured – the launch is in sight!

Our Quality Assured Care Home Accreditation Scheme is a project we hope will go a long way towards improving the standard and quality of care for people with Huntington's disease. Participating care homes will be required to meet a set of defined criteria, identified during extensive consultation by the Huntington's Disease Association as the principle requirements of quality care, in order to achieve HDA accreditation.

After many months of consultation, creating frameworks and associated procedures, the scheme is now in the pilot stage with two care homes, Yr Ysgol (Fieldbay) in Wales and Fairburn Mews (Exemplar) in England having signed up and submitted their portfolios. They are now due to proceed to the next stage of observation and assessment visits by an independent assessor during which interviews with staff, managers and family members will take place.

Once these visits have taken place, the assessor will review portfolio information, observation results and interview content and compile a report. This will be sent to an accreditation panel consisting of members of the charity's Patient and Public Involvement group HD Voice and selected members of the charity's board of trustees for a decision as to whether HDA Quality Assured accreditation for the named homes should be given.

If approved, a Quality Assured certificate will be awarded to the homes which will last for two years.

At the end of the pilot, the scheme will launch officially and care homes who have been involved in the consultation will be invited to take part. Subject to interest, we plan to review around eight care homes over the next year. Care homes will be able to register their interest in taking part in the accreditation on our website in the coming months.

Inbetweeners' day

The Inbetweeners' day is specifically aimed at people age 35-45 years with Huntington's disease in the family. The event enables many topics to be discussed in a safe and open environment, this year topics including mind and body wellness, forward planning and "Has anyone experienced.....?" were covered. The day went extremely well with 16 people attending.

Guides

We have been carrying out a complete re-jig of all of our guides, from our brand-new Carers Guide aimed at those caring for someone affected by Huntington's to our Nutrition and Behaviour Guides that aims to aid, not only family carers and those affected by Huntington's disease, but professionals alike. We have a number of guides aimed specifically at health and social care professionals – two of which, the Mental Illness and End of Life guides, have recently been updated.

Decisions, dilemmas and discussions

Decisions, dilemmas and discussions is a weekend for young adults aged 18-35 years of age with Huntington's disease in their family. The weekend is used to learn about Huntington's information from professionals, talking to others in the same situation and building friendships with people of a similar age. This year's weekend included a number of different workshops, including testing and options for having children and with 30 people in attendance we couldn't have been happier with how the weekend panned out.

In April, one of our amazing youth workers, Lilly D'Cruz, arranged a bowling event for children who live in families affected by Huntington's disease in the Swindon area. The event went extremely well and the children thoroughly enjoyed themselves! One child specifically mentioned that they had made a new friend due to the wonderful day. Parents expressed that the support, inclusion and advice offered was invaluable. Well done Lilly, thank you for your hard work and here's to more supportive social events.

Supported by BBC Children in Need

Bowling bonanza

Juvenile Huntington's Disease weekend

The lowdown!

Our Juvenile Huntington's Disease weekend is always one of the most popular events with 44 attendees this year including children affected by Juvenile Huntington's Disease, their families and carers. Taking place at the Calvert Trust in the Lake District, the weekend gives young people with JHD and their families an opportunity to meet other people in a similar situation, while also enjoying a great weekend full of exciting activities. It's also a chance for families to find out more about JHD from healthcare professionals with expertise in Huntington's disease, and by sharing experiences with other parents.

A note from Helen Santini, event organiser.

"As usual, the Calvert Trust organised a great mix of activities including horse riding, canoeing, zip wire, rock'n'rope, abseiling and swimming. The parents took part in separate sessions to enable them to meet and share, including a session with Hugh Rickards (neuropsychiatrist), a craft session and sailing."

"Just to talk to people in the same boat as us is priceless"

On the Friday night after people had arrived and settled in, they had the chance to relax or take an evening walk led by the Calvert Trust – the wet weather didn't dampen spirits and lots of the group still got out! On the Saturday evening, we had a circus skills workshop, a Disney-themed party and movie night.

"A huge thank you to the families who came, to the Calvert Trust who do such a great job, and to all those who volunteered to help at the weekend. Everyone gives so much, all in their own ways." Helen Santini

The weekend is very popular so we would encourage anyone interested in attending to get their booking form in early! If you are interested in the weekend or would just like to find out a bit more, do not hesitate to contact Helen Santini on 01279 507656 or email helen.santini@hda.org.uk

"No-one can understand your journey – only another who is living it too"

Christmas cards now on sale

Christmas will be round the corner before we know it!
Get prepared and order your cards today on

www.hda.org.uk/shop

All proceeds go towards funding our work.

Get in touch

For advice and support or to speak to a Specialist Huntington's disease Adviser

info@hda.org.uk
0151 331 5444
www.hda.org.uk/supportnearyou

Get involved

Become a fundraising volunteer

Email: **fundraising@hda.org.uk**
Phone: **0151 331 5445**
Web: **www.hda.org.uk/fundraising**

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